

Disability Issues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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Overcoming Challenges to Socializing

By Ray Glazier

Meeting people should be as natural as breathing, and it is just as necessary. Being with people is as important to your psychic health as breathing is to your physical health. However, whether you were born with a disability or have acquired one, meeting new people can be problematic, even if you are an extrovert by nature.

“Will they understand my disability?”
“What if they reject me?”
“What if they treat me like a freak?”
“What if they pat me on the head?”
“What if they smother me with kindness?”

The trick is to get beyond the “What ifs?” and move on to “So what?” You are who you are, not what others may first think you are. And there’s probably not much you can change about it, beyond being courteous, well groomed and nicely dressed. You have something to offer to those you’re about to meet. So, give yourself a hug and get out there. But, where to start? Well...

In this age of social media there are many no-cost options to connect virtually with others. **Facebook** and **Twitter** accounts are free to anyone with an Internet connection, using your Smart Phone, tablet, laptop, or desktop (yours or your local library’s). But be sure to set up your security or privacy settings to

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The Autistic Self-Advocacy Network Celebrates Autism Acceptance Month

By Kate Ryan



In the 1970’s, the Autism Society of America, an organization founded by parents of people with autism, declared April to be **Autism Awareness Month**. Forty years later, the Autistic Self Advocacy Network is taking back the reins from the non-disabled community and aiming to make **April Autism Acceptance Month** instead.

The **Autistic Self Advocacy Network** (ASAN) was founded in 2006 and became widely known in December 2007 after a successful letter-writing protest campaign led to the removal of the “Ransom Notes” billboards in New York City, which had compared autism to a kidnapper snatching children from society. Local chapters formed across the United States and in Canada and Australia, including an active chapter in the Boston area. ASAN developed close working relationships with other disability rights groups and became involved in a wide variety of initiatives and projects. Most recently in Boston, ASAN New England helped the disability organization ‘Second Thoughts’ to defeat a proposed assisted suicide ballot question, and organized a vigil for murdered people with disabilities on the **National Disabled Day of Mourning** on March 1st. Nationwide, in February 2014, ASAN was crucial in getting President Obama to include disabled workers who must be paid a certain minimum wage by federal contractors.

ASAN believes in the concept of neurodiversity. This is the belief that all brains and ways of thinking and being are valid, and a normal part of human existence. People are all different and their brains are different, too, but that does not mean anyone should be less valued than another, or that their opinions do not count. ASAN is one of the only disability organizations in the country that is 100% run by and for autistic people. ASAN was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism. Their activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research, and the development of Autistic cultural activities. They provide information about autism to the public through a number of different educational outreach and systems change related projects.

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protect your identifying information, like the city or town you live in if you are using your real name. A fake name can shield your identity, but perhaps also block friends from finding and connecting with you. Be careful of disclosing too much in the photos you post, as the background can give away your location, and a sweatshirt with the name of your school or town can also pinpoint where you are. In fact, based on your activity posts, sites actually track you and broadcast where you are or have been. And remember that indiscreet selfies have ruined reputations, not to mention political careers.

Online dating sites, and there are numerous ones specific to a disability clientele, usually are not free. Some offer free registration, but require paid subscriptions for the ability to send messages, which after all is the whole point. And you may get more than you bargained for. Fake photos, bogus ages and phony credentials seem to be the norm. Always arrange face-to-face meetings with strangers in a group of others you know or in a public place like a restaurant where there are many other people around. But don't get stuck with the whole tab.

Even if your disability is something rare, there is a local or online support group of kindred spirits you can start out to meet without a lot of anxiety. Get involved in groups whose identities, interests, and activities appeal to you. New friends with your same disability can give you pointers on approaching others, things that have worked for them. Family members or others who know you and your disability can provide good connections to people you'd like to meet; no need to 'go it alone.' Personal connections are safer and can put you on a familiar playing field when meeting someone new.

Approaching and meeting new people is much easier if you have something in common (forget 'same disability' and leave that behind) — hometown, hobby, school, religion, political party, favorite movies, favorite sports. Any of these can be the taking off point for a conversation. If you don't know anything about the person, ask questions about what they enjoy doing, where they are from, and what interests them. Everyone enjoys talking about themselves, and this approach lets others know you are interested in them, at the same time taking the focus off you, even if you are quaking in your boots.

Let me get personal for a minute: As a wheelchair user, I have always really identified with the title of Nancy Mairs' book, *Waist-High in the World* (Beacon, 1996). That title says a lot about how I feel when meeting people, or just cruising through a throng at a social event. I can often identify male acquaintances by their belt buckles and females by their panty lines. Not that I'm an exceptionally dirty old man — it's just that my seated eye level is about two feet south of that of most people. And craning my neck to make eye contact or to converse gets to be very tiring very quickly. My moderate to severe speech impairment confounds the problem, often leading people I meet for the first time to think I'm a lot drunker than I ever would be. For years, in fact for decades, this

double whammy kept me curled up in a ball inside my own head. I couldn't even take comfort in socializing with other wheelchair users because of the speech issue.

Three things wrought a change in my habit of limiting my utterances to a few words of no more than three syllables each and not trying to socialize with others: First a palate prosthesis improved my speech volume and enunciation to some degree; secondly my new power chair has a seat elevation function that can make me 18 inches taller. But thirdly, and most importantly, I realized that people are usually more interested in talking to me than listening to me anyway, and I'm down with that. I discovered that a short question directed at them, about them, often elicits a slew of interesting information that quickly allows me to assess the trajectory of our future association, or disassociation as the case might be. The only downside I've found to this strategy is that sometimes it elicits embarrassingly explicit, even intimate personal details, leading to my needing to signal 'Too Much Information.' Some people treat our conversations like they are talking with a priest or a psychiatrist. And I am far from either.

Raymond E. Glazier, Ph.D., formerly of Abt Associates Inc. in Cambridge, is an SSDI beneficiary who returned to full-time employment in order to support himself and his family; now semi-retired, he is founder and Principal of disAbility Research Associates, LLC of Belmont, MA.

Disabled Friends Network

www.disabledfriends.net This site appears to be aimed at international friendships. Registration with e-mail address is required; has photos, blog posts, stories (many are product ads), and a Friend Finder. You can search for potential new pen pals by Disability Type [many categories, from Albinism to "Wheelchair bound" (sic)] and Location (Nations only, not cities, or even states within the U.S.).

FUN and FRIENDS CONNECTION

www.funandfriendsconnection.com A forum for people with intellectual and developmental disabilities, their families and caregivers to access positive recreational and personal enrichment opportunities via the World Wide Web. This MA site has community events with a current calendar, as well as seasonal recreation options, and a Friends section, for which registration with e-mail address, gender and birth date is required.

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From the Editor

Dear Readers,

During our long, cold, snowy, icy Winter, there were many times I wondered if I would ever walk outside again without fear of slipping on some ice hidden under a layer of snow. Thank goodness the warm sunshine has finally arrived to melt the last remaining piles of snow and ice, making it easier to travel outdoors with ease and freedom. Welcome back beautiful, warm, happy Spring!

For our regular readers, you may have noticed a small, but significant, change to our front cover — we added a sentence underneath *Disability Issues*. Did you notice it? This sentence is the guiding focus we have used for many years to select the type of articles we publish in the newsletter. The editorial board is pleased to make our mission more visible and share it with our readers to provide greater clarity about the purpose of *Disability Issues*.

Occasionally, we receive requests from readers to publish an article they've written or a reader asks us to write an article on a particular topic. In this issue, we are delighted to bring you both of these types of articles. A reader asked us to publish an article on socializing and meeting people, so we wrote it. Another reader who lives with Rheumatoid Arthritis submitted an article about his scuba diving experiences, and we published it. If you have a suggestion for a topic, a question for Ms. Love, or a written article that would provide relevant information to our readers, please send it to us. You may see it published in an upcoming issue!

Another way to get involved with *Disability Issues*, is to become a member of our editorial board. I invite people with disabilities, those with knowledge about disabilities, and who are enthusiastic about writing articles to contact cmmoran@partners.org if you are interested in learning more about being on the editorial board.

Enjoy this issue and take some time during the month of April to celebrate Autism Acceptance Month. When people with disabilities support individuals with a different disability than our own, we create a cohesive community that supports us all.

Marianne DiBlasi, Editor

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How Can YOU Benefit from an Independent Living Center?

By Jamie Mello

Within the state of Massachusetts, there are twelve non-profit Independent Living Centers (ILC's), also referred to as Centers for Independent Living, that work exclusively with individuals living with disabilities. People with disabilities seeking full integration into society created the ILC. The Centers are operated by people with disabilities and services are provided at no cost to the individual. All twelve ILC's have the same philosophy, wherein all services provided are consumer controlled.

Consumer controlled services operate on the belief that the consumer is the expert on their own needs, perspectives, life goals, and decision-making, especially in relation to the services they choose to receive or participate in.

Independent Living Centers provide services in the areas

Independent Living Centers offer services to people living with disabilities across all ages, life stages, and circumstances. Whether housing assistance is needed, access to PCA services, employment, or support in finding additional resources, the Independent Living Centers are always available to help

of peer mentoring/support, skills training, information and referral, as well as individual and systemic advocacy.

If you are interested in finding an Independent Living Center nearest you, visit the MASILC website: www.masilc.org. The MASILC website will help you locate an Independent Living Center based on your geographic location and provide you with their contact information.

Jamie Mello has a Master's degree in Social Work with a concentration in Health and Mental Health from Salem State University. She works at the Boston Center for Independent Living as a Youth Employment Advocate and a TIP Program Manager.

Taking Rheumatoid Arthritis to New Depths

Diving into the depths of the Atlantic off the coast of Rhode Island this summer was an experience unlike any other for David St. Martin. While the tropical fish, blue crabs and starfish left him in awe, what struck him most was the sensation of weightlessness. With pressure off his joints, he was able to relax in a way he never had before. Diagnosed at 2 years-old with polyarticular Juvenile Rheumatoid Arthritis, which has caused chronic joint pain, joint deformation, swelling, and stiffness, St. Martin has been living with the disease's crippling affects for more than 40 years. As a child, he was in and out wheelchairs and hospitals and even graduated Northbridge High School from a wheelchair. Although he went on to obtain a degree from Worcester State University, and is currently employed at WSU, he felt something was missing... he always wished he could be more active and possibly enjoy the outdoors like so many other people. However, "It (Rheumatoid Arthritis) affects every aspect of my life," he said. "I was in the mindset that outdoor activities were beyond my reach." But a couple years ago something changed in St. Martin, and he remembers the moment quite clearly. It was shortly after receiving another total joint replacement and he was home on the couch, watching TV. An activity that he felt became far too routine.

"I was sitting there and I just realized, there has to be something more than this," he said. He came to the point where he decided to turn his "disability" into "ability" and get involved in the vast world of outdoor sports that he had spent his whole life thinking he couldn't be a part of.

Searching the internet, he discovered several local organizations that help disabled people enjoy many outdoor activities. Through these organizations, he has spent the last

two years learning to sail with **Community Boating**, kayaking with **All Out Adventures** and even water skiing with **Northeast Passage**. "It (has) changed my life immensely," he said. "I spent so many years in and out of hospitals that even the times that I was relatively healthy; I wasn't focusing on being an active person."



David St. Martin and Scuba Made Easy Instructor, Deb Greenhalgh

The grant provides training and equipment to a disabled person to pursue scuba dive education. He began and recently completed his Open Water Scuba Diver Certification with **Scuba Made Easy** in Jamestown, Rhode Island.

Initially his hope was to inspire other people living with physical disabilities to realize that anything is possible, but he's found that his story resonates with people of all walks of life. "Disabled people would comment that they were inspired by what I've been attempting to do, but even nondisabled people who aren't as active say the same thing," he said. "I just want to show people who think they can't do something that if they reach out, they will find that there's help to accomplish everything they want in life."

Article is reprinted with permission from David St. Martin and the Blackstone Valley Tribune, originally published Sept. 13, 2013 edition of the publication.

Coping with a Visual Disability at Age 27

By Mary Grimley-Mason

Those of us with disabilities have developed many strategies to deal with daily life as well as the challenges from the ablest world we live in. I had a conversation with Jamie Mello, who has a visual impairment. We talked about her coping skills and advice to others.

Jamie is twenty-seven and has a visual impairment from glaucoma. Her disease was diagnosed shortly after her birth when she became another statistic of one out of fifty thousand infants born with the disease. She had sixteen surgeries to remove cataracts and relieve pressure before she was fifteen. Presently, she needs some accommodations for her disability, such as larger print on all materials, assistance in crowded public places and particular challenges with depth perception. She has fairly good vision in her right eye, but the vision in her left eye has worsened.

In response to a question about her family's attitude toward her disability, Jamie says, "A few of them have been in denial about my diagnosis. It isn't something they can see happening other than the unusually thick glasses I wear." But, Jamie continues, "My condition really is a learning experience for them as well as for me."

Growing up, Jamie found it challenging to make friends in school, particularly in middle school where she experienced some bullying. "Kids didn't understand my condition or why my glasses were so thick. I was picked on a lot. However, as I aged, I realized I had an opportunity to decrease the teasing by educating my peers.

Jamie feels her disability has affected her life in both positive as well as negative ways. Her decision to respond to her schoolmates by teaching them about her disease was, she says, "the first time I had taken advocacy into my own hands and it

was an empowering experience." In fact, her experience shaped her vocation and her career choice to become a social worker. She has both a bachelor's and a master's degree in Social Work and she presently works as a Youth Employment Coordinator at the Boston Center for Independent Living with young people between the age of sixteen and twenty-two who have diverse physical, mental and autistic disabilities.



Jamie Mello

Although Jamie has been excluded from even applying for some jobs in Social Work because her disability prevents her from driving a car, she says, "My disability has also enabled me to understand the barriers that my clients are facing." For instance, she points out that many people in our communities do not know how to approach or interact with persons with disabilities in public places such as the subway. I try to explain my condition and what assistance I may need. "It's the social worker in me!" she says.

About her future plans for making changes because of her disability, she says, "This question is rather challenging for me. There are times when I try not to think about a future as a blind person because it scares me. I know that I will eventually lose my sight permanently. I just don't know when. I have taken some steps to prepare myself for living without sight, such as learning Braille and using a cane."

Jamie summarizes her advice about coping to all people with disabilities. "Define a different way to do it."

Mary G. Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; *Life Prints: A Memoir of Healing and Discovery*, *Working Against Odds: Stories of Disabled Women's Work Lives*, and *Taking Care: Lessons from Mothers with Disabilities*.

HHS Strengthens Access to Community Living People with Disabilities and Older Adults

On Friday January 10, 2014, the Centers for Medicare & Medicaid Services (CMS) issued a final rule to ensure that Medicaid's home and community-based services programs (HCBS) provide full access to the benefits of community living and offer services in the most integrated settings. The rule, as part of the Affordable Care Act, supports the Department of Health and Human Services' Community Living Initiative. This initiative was launched in 2009 to develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living.

Under the final rule, Medicaid programs must support home and community-based settings that serve as an alternative to institutional care and that take into account the quality of individuals' experiences. The final rule includes a transitional period for states to ensure that their programs meet the home and community-based services settings requirements.

The final rule includes the following enhancements to Medicaid HCBS:

- Provides implementing regulations for new flexibilities enacted under the Affordable Care Act to offer expanded HCBS and to target services to specific populations;
- Defines and describes the requirements for home and community-based settings;
- Specifies that service planning must be developed through a person-centered planning process that reflects individual preferences and goals; and
- Provides states with additional flexibilities when designing and administering HCBS waivers.

Visit www.medicaid.gov/HCBS for more information regarding the Home and Community-Based Services available under Medicaid. Questions/concerns about the regulation can be addressed to: hcbs@cms.hhs.gov



Dr. Carol Queen
Good Vibrations Staff
Sexologist & Historian

Ms. Love recently met Dr. Carol Queen, sex-positive retail store Good Vibrations' Staff Sexologist. Dr. Queen is also the founding director of the Center for Sex and Culture in San Francisco, California, and an author of books and essays about sexuality. Kristen Cotter is the manager of the Brookline, Massachusetts branch of Good Vibrations.

Ms. Love shared some of our readers' questions with them, and what follows are their answers about aging and sexuality.

LOVE: Is there such a thing as being too old to have sexual thoughts, or too young not to have them?

QUEEN: No, sexual thoughts and desires are with many people throughout the lifespan, and at the same time, people at any point might be disinterested in sex. Sometimes this lack of interest is completely natural to them or their life circumstances. Sometimes it is a sign that something is wrong, physically or emotionally, since some illnesses can present with a loss of libido.

COTTER: There is a great sex education comic book (Yes! A comic book!) called *Not Your Mother's Meatloaf: A Sex Education Comic Book* by Saiya Miller and Liza Blay that illustrates Dr. Queen's point perfectly: "It is tempting to simplify the world of sex, love and relationships, not only to be able to explain it to children, but to be able to reckon with it ourselves. We want to believe that there is order in the play of life: Act One is childhood and innocence; Act Two is teenage life and discovery; and by Act Three we are supposed to have fully formed identity, and along with it, a roadmap to kissing, sex and love. In reality, few of us ever live these plays. We have wildly different versions of the script, with notes scribbled in the margins, lines highlighted and sections missing... We sculpt ourselves like clay, constantly shifting and molding ourselves with each new exposure." The point is this: Everyone experiences life differently. It would be very difficult, if not impossible, to set an age limit on having sexual thoughts... as most of our thoughts, sexual or not, are influenced by our experiences in life, regardless of our age, abilities or gender.

LOVE: Many readers have asked me if they need to be concerned about casual sex and the health of a partner if they are older; they comment that they don't have to think about reproduction at this point in their lives. If they do have to be concerned, how do they approach it?

Aging and Sexuality

By Ms. Love

QUEEN: Yes, indeed you do have to think about health issues. The only one you may NOT have on the table now is contraception. Older people are still susceptible to sexually transmitted conditions, and many older people whose monogamous relationships have ended due to death or divorce are entering the dating pool with no idea that condoms and other safer sex modalities are necessary; hence there are more germs being passed than need to be! Have a look at the website, Safer Sex for Seniors, to get caught up <http://safersex4seniors.org/>

LOVE: A reader wrote me the following: "My spouse and I have been married for many decades. Together, we have multiple kinds and severities of disabilities and health issues. We still excite each other, but do you have any suggestions for new things to try as we experience more and more health issues?"

QUEEN: Two things that are very easy to incorporate into a long-term sexual relationship are Tantric practices (these can be great for people whose bodies are changing) and role play, because the latter allows you to explore different personas and fantasies without requiring any other changes to your sexual repertoire.

COTTER: Folks new to Tantra should check out *Urban Tantra: Sacred Sex for the Twenty-First Century* by Barbara Carrellas, and *Ecstasy is Necessary: A Practical Guide to Sex, Relationships and Oh So Much More*, also by Barbara Carrellas (who is worth a google on her own if you are curious about "Thinking Off" - people who can "think" themselves to orgasm! No touch required or needed!). Sometimes, folks interested in role play might feel uncomfortable or awkward the first couple of times they try it. Don't let this discourage you. Try reading erotica aloud to a lover, so that you become comfortable physically saying steamy things to your partner.

More of this interview on aging and sexuality will appear in future columns by Ms. Love. Good Vibrations' website is <http://www.goodvibes.com>, and the Brookline store can be reached at phone 617-264-4400. Older adults may ask for the senior citizen discount when they check out their purchases at the store.

The Love and Intimacy Corner welcomes questions and requests for topic areas from readers; please send all suggestions to DI.LoveandIntimacy@gmail.com



Are you a family caregiver for a loved one with special needs, a chronic illness, or a disability?

2nd Annual CARE Conference Connecting and Advocating Respite for Everyone

3 R's of Respite Refresh-Reflect-Recharge

Date: Friday, May 9, 2014

Time: 8:00am to 3:00pm

**Where: Best Western Royal Plaza Hotel
181 Boston Post Rd W
Marlborough, MA 01752**

The MLRC is excited to offer this FREE conference for any family caregiver in Massachusetts. Keeping with this year's theme, 3 R's of RESPITE, workshop offerings will include both experiential topics like yoga and expressive art as well as informational topics like estate planning and advocacy.

We are fortunate to have Lon Kieffer, nationally known as DOC, Defender of Caregivers, as the keynote speaker.

Some financial assistance to cover respite expenses while you attend the conference is available.
Request an application when you register!

VISIT

www.massrespite.org and click to REGISTER

Email questions to
conference@massrespite.org

Accessible Recreation Fair

May 31, 2014

10am - 3pm

Artesani Park in Brighton MA

The Department of Conservation and Recreation's (DCR) Universal Access Program (UAP) will offer a free fun-filled day of celebrating Accessible Outdoor Recreation available for individuals, families and friends of people with disabilities. This is the place to come find out about accessible recreation programs offered by multiple organizations in the Boston area and beyond.

Activities will include a cycling fair with an assortment of accessible cycles available for use; other adaptive recreational activities, including hiking, letterboxing, face painting and interpretive programs; music; snacks, including Starbucks Coffee, Legal Seafood's Chowder Mobile and much more!

Pre-registration is highly recommended, especially for use of equipment and to request an ASL interpreter. Call Gigi at 617-626-1294.

For more information on DCR's Universal Access Program and a schedule of activities, and to confirm program status, call (617) 626-1294 (voice) or 413-577-2200 (TTY) or visit <http://www.mass.gov/eea/agencies/dcr/massparks/accessibility/>



The Healthy Living Center of Excellence

The Healthy Living Center offers "My Life, My Health" programs for people living with chronic health conditions such as diabetes, heart disease, chronic pain, and others. The classes are designed to empower adults to take a more active role in their health care by focusing on incremental behavior changes to achieve better health.

The Center provides workshops throughout Massachusetts. To learn more about programs available in your area, call 978-946-1211 or visit <http://www.healthyliving4me.org> and click on "Programs" or "Workshop Schedule".



Disability Issues

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The Autistic Self-Advocacy Network - continued from page 1

ASAN welcomes people with all types of autism, as well as autism allies. Their members include verbal and non verbal people, people who were diagnosed young in life and those not diagnosed until their sixties, people who range from a variety of cultural and socio-economic backgrounds. The one thing in common is that all of the members agree that autism is not the big, bad, scary monster that popular media so often makes it out to be. Autism is a disability, but it is also a gift, which can give people a unique way of looking at the world and solving problems within it.

Awareness, says ASAN, is not enough; they want acceptance, acceptance of their quirks, appreciation of their strengths, reasonable accommodations of their differences. Despite what you may hear on daytime television, you cannot cure autism; you can only learn to mask it. ASAN questions societal paradigms that say that people have to mask it at all. What is so wrong about being weird? What is so wrong about breaking societal rules, as long as you don't hurt anyone, what is wrong with flapping your hands in joy or obsessing over the wonder of trains? There is nothing wrong, autistic advocates say. There is nothing wrong with me; there is nothing wrong with you. Let's stop fighting over the best ways to 'treat' autism and instead, look at the whole person and the whole of their life. Let's celebrate the wonders of our brains and

accept everyone for who they are.

For more information on the Autistic Self-Advocacy Network, visit <http://autisticadvocacy.org>

Kate Ryan is a disability advocate and active member of ASAN New England. She has a master's degree in disability studies and is currently looking for work in the disability field. In her spare time, she campaigns to change April to Give Autistics Chocolate Month. (Yes, that's a joke. Yes, autistics do sarcasm.)

Why "Autistic"?

Isn't it "Person with Autism"?

The Autistic self-advocacy community usually, although not fully, prefers the word 'Autistic' to describe themselves, because they see autism as a part of their identity which they cannot be separated from, just as it's impossible to separate a person from the color of their skin. Autism resides in every cell of their body and in everything they do. Therefore, saying "Autistic person" affirms and validates the wholeness of the person's identity.